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Training Ethical and Professionalism Aspects of Dealing with Health-Related Datasets

Date: 20-21 November 2025

Location: Academy for Music, Kongresni trg 6, 1000 Ljubljana

Agenda item	Time
Thursday 20 November 2025	
Registration	08:30-09:00
Welcome and opening chair (Damjana Rozman)	09:00-09:15
Framing Lecture: **Igor Švab** – *Why Ethics and Professionalism Matter in Health Data Use*	09:15-09:45
Participant Introductions & Expectations – Facilitated round-table	09:45-10:30
Coffe Break	10:30-11:00
Mini Lecture and discussion. **Gerhard Fortwengel:** *From Consent to Consequence: Rethinking Digital Ethics in Health Care and Research.*	11:00-12:00
Mini Lecture and discussion. **Giovanni Spitale:** *Ethical issues for data management in healthcare systems*	12:00-13:00
Lunch Break	13:00-14:30
Organisation into the 6 working groups on chosen themes	14:30-15:00
Work in Groups on a chosen scenario (two seminar rooms)	15:00-17:00
Reflections & Lightning Reports from the Groups	17:00-17:30
Dinner	19:00

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Agenda item	Time	
Friday 21 November 2025		
Preparation of the groups for the presentations	08:30-09:30
Final Group Presentations (15 + 5 mins Q&A per group)	09:30-11:30
Wrap-up Discussion	11:30-12:00
Presentation of certificates & Departure	12:00-12:30

Framing Lecture

Prof dr. Igor Švab: Why Ethics and Professionalism Matter in Health Data Use

The lecture offers a humanistic and educational framing of the workshop's theme from the perspective of a medical school dean and a family doctor. As the complexity and scale of health data continue to grow, ethics and professionalism remain essential across all areas of research. Drawing on decades of experience in patient care and medical education, the speaker will reflect on the responsibility of academic institutions not only to produce competent researchers, but to cultivate ethically grounded professionals. Participants will be invited to engage with these issues through the lens of clinical practice—where humility, curiosity, and a shared commitment to trust and social accountability must guide decisions we make.

Mini lecture

Prof. dr. Giovanni Spitale: Research with Health Data: Ethical Issues, Risk Mitigation, and Data Management Practices

Health data offers immense potential for advancing medical research, but it also raises pressing ethical questions. This lecture and the following workshop explore the complex landscape of working with health-related data, from informed consent and data anonymization to governance challenges and cross-border sharing. Participants will gain practical insights into identifying ethical risks, applying mitigation strategies, and implementing responsible data management practices. Designed for researchers and data stewards, this session bridges theory and practice to foster ethically sound research with health data.

Mini lecture

Prof. dr. Gerhard Fortwengel: From Consent to Consequence: Rethinking Digital Ethics in Health Care and Research.

Digital ethics in healthcare and research is reshaping how informed consent is understood and practiced. Technologies like AI, EHRs, and health apps offer new opportunities—but also raise ethical concerns. Digital platforms can enhance consent through multimedia, personalization, and traceability. However, they may oversimplify complex information or overwhelm patients. AI-driven decisions challenge transparency and accountability, making consent harder to validate. Patients often don't understand how algorithms influence diagnoses or treatments. Broad consent models allow future data use but reduce patient control and clarity. This can erode trust and compromise ethical standards in research. Digital exclusion and consent fatigue risk marginalizing vulnerable populations. Ethical design must prioritize clarity, transparency, and patient empowerment. Consent should evolve into a continuous, trust-based dialogue—not a one-time checkbox. Rethinking digital ethics means centering human values in every technological advance. In this brief introduction, we aim to present and summarize key questions, which will then be explored in more detail within working groups to encourage joint discussion and deeper analysis.

Themes for working groups

Prof. dr. Gerhardt Fortwengel

1. *Consent vs. Comprehension: How Informed Is Informed Consent?*

Participants explore the gap between legal consent and actual understanding in digital health applications. Where does formal agreement end—and where does true patient education begin?

2. *Data Trails in Healthcare: Between Benefit and Surveillance*

This group discusses how health data is collected via apps, wearables, and research. What ethical boundaries exist between innovation and individual rights?

3.   *Ethical Red Flags: What Would Make You Say No?*

Participants discuss real-world scenarios where digital health solutions raise ethical concerns. Where do personal and societal boundaries begin to blur?